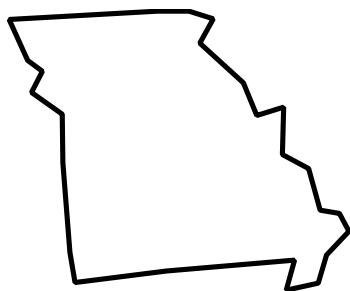


# Show Me Change:



**Building A Participant-  
Driven System For  
Missourians With  
Developmental  
Disabilities**

**Final Report**

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**The Missouri  
Customer Leadership Initiative**

**August 5, 1998**

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## Building A Participant-Driven System For Missourians With Developmental Disabilities

The Missouri  
Customer Leadership Initiative  
Final Report -- August 5, 1998

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# 1. Background

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**D**evelopmental disability service systems are changing in every state. In response, the Missouri Planning Council for Developmental Disabilities initiated the **Missouri Customer Leadership Initiative**. This Initiative was composed of people with disabilities, family members and others who represent relevant constituencies. Beginning in the Summer of 1997, we met nearly monthly during two-day retreats. During these working sessions, we worked to:

- ❑ Create our vision for developing a community-centered response to developmental disabilities;
- ❑ Establish principles to guide overall system design and service delivery;
- ❑ Understand the circumstances surrounding service delivery for people with developmental disabilities, nationally and in Missouri;
- ❑ Become familiar with the actions unfolding around the country to reform and improve developmental disability systems.
- ❑ Consider what must be done in Missouri to assure that the entire developmental disabilities service system operates in ways that are consistent with our stated guiding principles.

Throughout, information and discussion concerning the factors that are driving change nationally and in Missouri guided our work. Since the early 1970s, thousands of people across the country have worked hard to establish “community based” systems for supporting people with developmental disabilities. Public institutions still exist, serving

## Summary

Due to funding limitations, growing service waiting lists and evolving service practices, the developmental disabilities field is changing. In response, the Missouri Planning Council for Developmental Disabilities convened a working group to consider what could be done to re-structure the long-term support systems for people with developmental disabilities.

The Initiative established its vision for the future and a series of principles to guide the way. A series of recommendations were also developed revolving around: (a) employment, (b) participant-driven supports, (c) the role of the Regional Councils, and (d) building capacity for a person-centered system.

Note: A project Executive Summary is available through the MPCDD.

about 55,000 people in 46 states. However, the dominant service response is in the community, revolving around an array of service options including supported living, group homes, supported and sheltered employment, day habilitation, family support and a variety of ancillary supports.

Using 1996 national data, researchers report that 64% of the 388,941 persons living in publicly funded out-of-home settings reside in places serving 15 or fewer persons. Half of this total -- 194,990 people -- are living in settings for six or fewer, an increase of 51% from 1992 (Braddock, Hemp, Parish & Westrich, 1998). Regarding expenditures for developmental disability services, these same researchers found that in 1996, 68% of the \$22.8 billion that states spent on developmental disabilities services paid for services in the community. This compares to 44% of expenditures in 1986 and 25% in 1977.

These trends are pleasing to any that support community oriented responses to disability. Yet the field stands poised on the brink -- some say precipice -- of change over how service systems are structured and managed. A 1997 survey of state directors of developmental disability services "revealed that about half of the responding states were at some stage of launching a major change initiative. In most of the remaining states, major system change was actively discussed" (Smith & Gettings, 1998; p. 1). Among the several factors driving change, three of the most powerful are:

- ✓ The push for **self-determination** whereby systems are structured so that service recipients influence policy, and individuals have the freedom and authority to determine the substance and texture of their own lives, including control over the resources allocated for personal services or support.

As important as *what* services or supports are delivered, is *how* such assistance is offered.

Until recently, professional judgment was more heavily weighted than the choices and preferences of service recipients. In addition, the choices available to people with disabilities were restricted to the residential and vocational slots available. Emerging practice, however, dictates that people with developmental disabilities should play leading roles in determining the substance of their lives, with a complementing emphasis on community inclusion and participation. Services are developed as needed to support these preferences. Moving past traditional professional or supply dominated approaches, the field is struggling to become more responsive to the demands of service recipients -- to promote and honor *self determined lifestyles*.

### ***Self-determination***

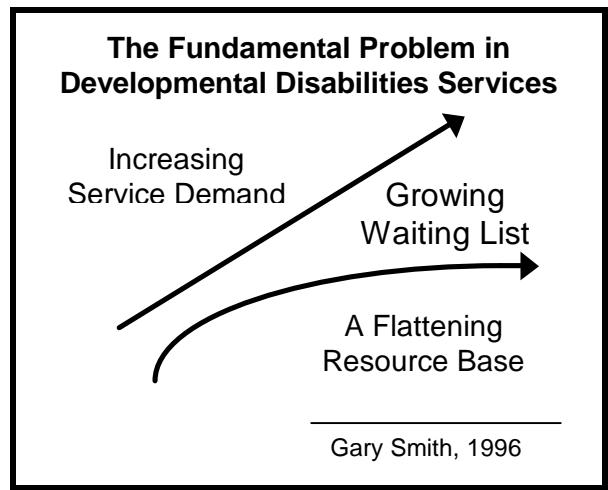
To act as the principal causal instrument in one's life and to make choices and decisions regarding one's chosen lifestyle independent of undue influence or interference from others.

Wehmeyer, Kelchner & Richards (1996).  
In the *American Journal on Mental Retardation*, 100(6), 632-642.

- ✓ **Demand will grow for developmental disability services.** America is graying. People are living longer and that includes people with disabilities, circumstances that will drive the demand up for services, especially ones to accommodate seniors with disabilities. In addition, the parents of many adults with disabilities are growing too old to continue to provide care at home. Middle aged baby boomers that had children with disabilities are finding that their children are now aging into the adult system. Consequently, the pressures placed on the long-term supports system for adults with disabilities can only grow over the next several years.

Researchers at the University of Minnesota (Prouty & Lakin, 1998) estimate that state-local service systems would need to grow by 24% simply to meet current demand. Echoing such research, a recent National Arc study concludes that the nationwide shortfall of community support services has reached crisis proportions for people with mental retardation and their families. According to the report, more than 218,000 requests for support remain unanswered for people with mental retardation and their families (The Arc, 1997).

Admittedly, waiting lists are difficult to track. There is no standardized way to collect the information, nor is it often verified. Also, there is no easy way to estimate the "urgency of need" of any on the waiting list. As a result, some argue that the numbers are overstated, while others counter that the uncertainty in data collection means that the real numbers are under reported. While there are problems with waiting list data, the numbers cannot be discounted. The numbers – and accompanying personal stories -- reflect a growing problem for policy makers.



- ✓ The need to demonstrate **fiscal responsibility** for the resources already allocated to developmental disability systems. Public outlays for developmental disability services increased at an after inflation rate of 168% between 1977-1996 (Braddock et al., 1998). Over the past few years, growth has averaged about 9-10% per year. Yet there are strong indications that public support is eroding for expanding a variety of government programs. While Smith (1998) observes that interest in some programs (e.g., public education, corrections, law enforcement) remains strong, other social service initiatives may be at risk. Certainly, there is continued concern for containing Medicaid spending at the federal and state levels. He concludes that "a strategy based on the assumption of a steady, double digit growth in public funding for developmental disability services is almost certain to fail" (p. ii). The

result is the demand for fiscal efficiency, a call that has been answered by those wanting to inject managed care strategies into developmental disability systems.

Mixing together the concern for funding and an increased demand for services, the developmental disabilities field is faced with an enormous problem. If present circumstances unfold without modification, the outcome can only be an increase in the waiting list. Despite encouraging isolated events where “new money” is allocated to state developmental disability authorities to accommodate portions of the waiting list (e.g., as in LA, NJ or OR), the field must face up to the sobering challenge it faces. No further dramatic increases in funding will be forthcoming, the demand for services is increasing, and means must be implemented to make service systems more efficient; That is, to do more with the resources already available.

What follows are the primary outcomes stemming from our work. The remainder of the document is divided into four sections:

**Section 2. Guiding Principles:** This section presents a series of guiding principles developed by the project participants, including “core” principles that must lie at the heart of any service system, and other complementing principles to guide service delivery and policy in Missouri.

**Section 3. The State of the State:** This section provides a data-based background to the project, offering information on the status of services, nationally and in Missouri.

**Section 4. Recommendations:** This section offers a series of policy recommendations that -- if enacted -- help assure that services are delivered in ways consistent with the guiding principles.

**Section 5. Concluding Remarks:** This final section offers a final word from participants regarding what we must all do in Missouri to translate the recommendations into practice.

Overall, this Final Report charts a new course for Missouri in supporting people with disabilities. It outlines changes that are needed to put community inclusion, self-determination, fiscal responsibility and collaboration at the forefront of how we support people in our communities.

# 2. What We Believe

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The following principles illustrate what Initiative members value most concerning policy and practice for people with developmental disabilities in Missouri. We recognize that current actions in Missouri are not always consistent with these principles.

The principles are grouped according to the areas contained in the state's "Certification Principles" for Home and Community Based waiver services:

- ∂ Community Membership,                          ≠ Meeting Basic Needs,
- Self-determination,                                ≡ System Management.
- ÷ Rights,

All these principles are shown below by category. Spanning all our beliefs is an overarching "**core principle**." This core principle describes who is in control of how and where resources are allocated.

Resources for supports in the State of Missouri must be allocated and expended from a person-centered perspective rather than a provider centered perspective. Individuals must be in control of their allocated resources for services and supports and how they are delivered.



There exists a fundamental difference between a person and a provider-centered approach. It has to do with a shift of power (See the illustration on the next page.) A person-centered system will embrace the principles that follow. These guiding principles for Missouri's developmental disabilities systems must apply to all eligible people of all ages regardless of the severity of their disability.

<b>Provider Centered System</b>	<b>Person Or Participant Centered System</b>
<ul style="list-style-type: none"> <li>□ Resources for support are given to those providing the supports. Decisions of what, how, and where supports are to be provided, at best, may be a shared activity with the person who is receiving the supports. However, more often these decisions are made with little direction from the person involved. Decisions are owned or controlled by individuals empowered by virtue of professionalization or position.</li> <li>□ Control of who provides the support almost always rests with the provider organization.</li> <li>□ People are labeled as “slots”.</li> </ul>	<ul style="list-style-type: none"> <li>□ Control of resources, decisions of how and where money is spent rests with the person who needs supports, and/or his or her family, friends or advocates.</li> <li>□ Control of who provides supports rests with the person and/or his or her family, friends or advocates.</li> <li>□ People are valued as people.</li> </ul>

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## The Principles

### ① Community Membership

- ↑ All people with developmental disabilities belong in their community.
- ↑ Community inclusion is the basis of the services and supports that people receive. The concept carries the following characteristics:
  - 4 People with developmental disabilities have contributions to make in our communities that are equal in worth and value to those of other citizens.
  - 4 People with developmental disabilities are supported in their communities, near families and friends.
  - 4 People with developmental disabilities have the same opportunity as other citizens to live in homes of their own, by themselves, with their family, or with friends of their choice.
  - 4 People with developmental disabilities have the opportunity -- as do other citizens -- to find and hold competitive jobs and/or otherwise contribute to the community.

- ↑ Services and supports promote a positive image and awareness of people with developmental disabilities.
  - ↑ Services and supports provide opportunities for people with developmental disabilities to be valued members of the community, making contributions as well as receiving needed supports.
  - ↑ The system promotes the use of community resources, and, in so doing, builds community capacity.
  - ↑ Services and supports promote the centrality of the family in the lives of individuals with developmental disabilities.
- **Self-determination**
    - ↑ People with developmental disabilities and family members have options in all areas of services and supports.
    - ↑ People with developmental disabilities are informed of the variety of options, as well as the benefits and risks associated with the choices they make.
    - ↑ People with developmental disabilities have the opportunity, with support as needed from those who care about them, to make choices and decisions about their every day lives.
    - ↑ Individuals have control over their allocated resources.
    - ↑ People with developmental disabilities can modify services and supports to accommodate their changing needs.
  - ÷ **Rights**
    - ↑ People with developmental disabilities have the same rights and responsibilities as other citizens, including the opportunity and responsibility to direct their own lives.
    - ↑ People with developmental disabilities are listened to and treated equally as other citizens without assumptions based on their disabilities.
    - ↑ People are not discriminated against due to cultural or ethnic differences.
    - ↑ People with developmental disabilities have the right to determine their needs and assume responsibility for the choices they make and the consequences of their decisions.
    - ↑ Services and supports are delivered in ways that recognize the centrality of the family in the lives of individuals with developmental disabilities.

- ↑ Individuals have a right to grieve any decision or process that affects their quality of life.

## ≠ Meeting Basic Needs

- ↑ The system is responsive to individual needs, providing help when and in the manner that people need assistance.
- ↑ People with developmental disabilities, family members and others have peace of mind that services and supports are reliable, both today and for the future.
- ↑ Individuals have personal security in their everyday lives.
- ↑ People with developmental disabilities, family members and others are confident that publicly-funded services assure and promote:
  - 4 Good health;
  - 4 Individual safety, including protection from abuse or harm;
  - 4 Individual well-being, comfort and security;
  - 4 Individual rights and freedoms.

## ≡ Systems Management

- ↑ There is an ethical responsibility to provide services in accord with these principles and “choice” shall not be used as a reason for shirking that responsibility.
- ↑ Services and supports are accessible and easy to use.
- ↑ Services and supports nurture the family structure, fostering and enhancing family unity.
- ↑ Ethnic and cultural differences are recognized, valued and included in designing services and supports to fit individual needs.
- ↑ The system is an active partner with people with developmental disabilities and families by providing helpful and accurate information about choices.
- ↑ The system values and supports the choices made by individuals and families.

- ↑ The system shall maintain effective oversight to ensure that individual rights are honored.
- ↑ There is a grievance process available to address complaints without retribution.
- ↑ People with developmental disabilities and family members are informed, active and equal partners in policy making.
- ↑ There is collaboration among all stakeholders.
- ↑ Direct support staff are well trained, competent, adequately compensated, and supported and respected by their employers.
- ↑ The system promotes cost effectiveness, and any savings are reinvested in services and supports.

# 3. The State Of The State

Over the past 25 years services to people with developmental disabilities have undergone remarkable change. Central to this change was a *shift in focus from the institution to community-based facilities*. While conditions improved in the institutions, through the 1970's and 80's buildings were purchased or built in the community. Staff were hired and trained. A "facility-based" community system was born.

Missouri followed this trend. In recent decades, Missouri invested public resources to: (a) improve conditions at state habilitation centers, and (b) establish a facility-oriented community response to address the needs of people with developmental disabilities. Thousands of Missourians worked hard during this period to achieve these ends. Their work has resulted in an array of services to support people with developmental disabilities, including residential, vocational, family and other essential services.

Backing these direct services, an infrastructure evolved both to fund and manage the service system. Four primary funding sources include Federal Medicaid money, state tax dollars, county Senate Bill 40 mill tax dollars, and contributions from service recipients (e.g., Supplemental Security Income). In 1997, 486.5 million was spent on developmental disability services in Missouri. We recognize that a sizable number of dollars are contributed as charitable donations, mostly to private service providers. This report does not include a count or analysis of those funds.

Management of the service system is divided among various state agencies, such as the:

- ✓ Department of Mental Health and its Division of Mental Retardation and Developmental Disabilities (DMRDD),
- ✓ Department of Elementary and Secondary Education and its Divisions of Special Education and Vocational Rehabilitation, and
- ✓ Department of Social Services and its Division of Medical Services.

In addition to these agencies, local Senate Bill 40 County Boards also play a key role in systems management.

Illustrating these circumstances, the accompanying table (next page) shows the money spent in Missouri in 1997 on developmental disability services, and what it was spent on. Beyond these aggregate numbers, we examined state funding and service utilization patterns in greater detail (See Appendix A). Further, we compared Missouri's patterns with:

- ✓ The spending and service utilization patterns of neighboring states and national averages,
- ✓ Funding and service trends in the field that emphasize community integration, self-determination and fiscal responsibility, and
- ✓ Our own guiding principles (See Chapter 2).

<b>The Sources of Money</b>			<b>What the Money Bought</b>		
Missouri tax dollars	\$196.8M	40.3%	Residential Service	\$323.2M	66.4%
Federal Medicaid money	\$189.6M	39.0%	Daytime services	\$71.3M	14.7%
Senate Bill 40 tax money	\$46.0M	9.5%	Family supports	\$13.3M	2.7%
Consumer SSI	\$26.1M	5.4%	Other community	\$41.2M	8.5%
Other sources	\$28.1M	5.7%	Service Coordination	\$27.8M	5.7%
<b>Total</b>	<b>\$486.5M</b>	<b>100%</b>	<b>Total</b>	<b>\$486.5M</b>	<b>100%</b>

Source: Services and supports for Missourians with developmental disabilities: Where the dollars come from and go to. -- See Appendix A.

Based on our discussions, we find that:

**1. Many Missourians who are eligible for services remain on waiting lists.** The amount of money spent on developmental disabilities in Missouri in 1997 totaled \$486.5 million. Within DMRDD about 24,445 people were served, while the total number of all those served from all sources of money could not be accurately determined. The services these individuals receive range from service coordination to around-the-clock supports. The number of people on waiting lists in Missouri is not precisely known, since the number is not systematically and reliably tracked across the state. A national Arc study estimates that in Missouri 1,786 people are on waiting lists (The Arc, 1997). Meanwhile, in June 1998, DMRDD reported that 1,181 eligible individuals across its 11 Regional Centers were on waiting lists. These are people who have been found to need services, but are not receiving them.

The Missouri state population stands at about 5,414,000 people. A prevalence rate for developmental disabilities of 1.8% suggests that approximately 97,452 people in Missouri have a developmental disability. Having a developmental disability means that a person has substantial problems in meeting the challenges of everyday living. Not everyone with a developmental disability needs or wants government-funded services. Families and communities freely support many individuals. But the fact is that today there are people known to the system who have been identified as needing supports but who are not receiving them. There are others who today receive services, but the services are not the right kind. There are still others who

will face crisis because their parents are aging and will not be able to continue to support them. When people are consigned to a “waiting list”, the simple fact is that the public system is not meeting their needs.

When the scope of Missouri’s system is compared to other states, Missouri’s system emerges as “about average”. But we know that “about average” means that many people will not be receiving the supports they need. Nationwide, “about average” means that there is a large and persistent shortfall in the capacity of public systems to deliver necessary services and supports. So it is in Missouri.

At issue is whether or not this fact is acceptable to Missourians.

- 2. The prevailing Missouri service system for people with developmental disabilities is not person-centered.** Our core principle clearly articulates that: (a) resources for supports in Missouri must be allocated and expended from a person-centered perspective, and (b) individuals must be in control of their allocated resources for services and supports and how they are delivered. Further, our service principles emphasize community inclusion and citizenship over other forms of services that congregate or segregate people with disabilities from their communities.

In specific, we find that in Missouri:

- ✓ There is a strong facility orientation regarding where people live. (See Appendix A). Missouri spends a great deal of its resources on service options that emphasize facility over community inclusion. For instance, 2,828 of the 8,010 (35.3%) people who received residential services in 1997 lived in facility oriented options. These included:
  - ⇒ 1,381 people residing at habilitation centers, where the census has remained largely unchanged since 1993,
  - ⇒ 1,314 more in nursing homes, ranking Missouri 5<sup>th</sup> nationally in terms of the number of people with developmental disabilities relative to state population who are served in these kinds of facilities, and
  - ⇒ 133 people living in non-state operated community ICFs-MR.

"Every time we identify a need in this field, we build a building."  
Gunnar Dybwad

The costs for these services amounted to \$151.3 million of the \$323.32 million (46.8%) spent on residential services. Broken down by category, this included \$115.9 million (36% of the total) spent on habilitation centers, \$28.8 million (9%) on nursing facilities, and \$6.6 million (2%) on community ICFs-MR.

The table on the next page illustrates these findings, adding a comparison of these patterns with other residential options that are more community centered

(i.e., Home and Community Based community group homes, other non-waiver residential services). As shown, a significant proportion of residential resources is spent on relatively fewer people who live in facility-based options. In addition, about \$55,562 per person is spent on facility-based options, compared with \$33,173 per person that is spent on alternative community services.

**Comparison of Service Use and Spending Patterns In Missouri  
For Residential Services in 1997**

	Number Served		Money Spent		Annual Cost/Person
Facility-Based Options (Habilitation Centers, Nursing Homes, ICFs-MR)	2,828	35%	\$151.3	47%	\$55,462
Community Based Options (HCB Services, Other non-waiver residential)	5,182	65%	\$171.9	53%	\$33,193
Totals	8,010	100%	\$323.2	100%	

Source: Services and supports for Missourians with developmental disabilities: Where the dollars come from and go to. -- See Appendix A.

- ✓ There is also a strong facility orientation related to where people in the community spend their day. The state's primary daytime supports for people with developmental disabilities who live in the community are day habilitation programs and sheltered workshops. Nearly 5,000 people receive day habilitation services funded by the state's Home and Community Based Waiver. Approximately another 8,100 people with developmental disabilities are employed at about 90 sheltered workshops across the state.<sup>1</sup> Other community options that emphasize support over facility, such as supported employment, are available in Missouri, but they are not frequently utilized. Fewer than 500 people receive supported employment services through DMRDD's HCB waiver, while others receive such services through vocational rehabilitation agencies and Senate Bill 40 Boards. Yet these options -- and their associated dollar investments -- do not nearly match the availability of facility based options.
- ✓ Missouri has policies in place that discourage people with developmental disabilities from working. Many people with developmental disabilities want to have an integrated community job -- a regular job. A regular job should mean that they are able to use the money they earn to support themselves. If the aim is that people become more independent and less reliant on the public system,

<sup>1</sup> Information regarding Missouri's sheltered workshops is available on the internet through the Department of Elementary and Secondary Education.  
Contact: <http://services.dese.state.mo.us/divspeced/shelteredworkshops/index.html>

then they need to be able to keep the dollars they earn.

But Missouri has various policies in effect that go in the opposite direction. When people with developmental disabilities “earn too much,” they face the loss of Medicaid eligibility or can find themselves having to turn over what they earn to the state in order to maintain eligibility. Missouri’s policies in this respect are more punitive than federal policy dictates and less supportive of people benefiting from work than is the case in many other states. The signal that Missouri is sending to its citizens with developmental disabilities is that their getting a regular job will not allow them to get ahead. Missourians with developmental disabilities who get a job are taxed very heavily. This makes no sense. These policies need to change.

- ✓ People with developmental disabilities have little or no control over the funds allocated to them. At the core of a person-centered system is control over the resources used to provide one’s services. Under terms of Missouri’s Home and Community Based waiver participants are entitled to “freedom of choice” regarding their Medicaid provider; Individuals are free to choose their provider and to switch providers. This is an important freedom, though its potential is undercut by the absence of preferred and available service options (e.g., for supported employment) and inflexibility in the system that limits the choices people have regarding how they might spend Medicaid dollars.

Aside from Medicaid funded services, resource allocations are tied more to the provider than the service recipient. There are exceptions, such as the Choices For Families voucher program and the new Family Directed Support Program. These initiatives offer families great flexibility in spending their allocations. Overall, however, individuals cannot easily take the funds used to serve them from one provider and move them to another, or take the funds with them if they relocate. Many argue that the absence of such portability makes the system less effective and efficient than it could be. People simply are not free to “shop around” for the best services in terms of cost, preferences and outcomes.

Overall, the evidence in Missouri illustrates that policy and practice generally is not “person-centered” and does not typically favor community inclusion. At issue is whether or not this fact is acceptable to Missourians.

- 
- 3. Systems change unfolds too slowly in Missouri without a proactive or collaborative commitment to a common vision.** Certainly, over the past 25-30 years the services in Missouri that are available to people with developmental disabilities have changed. And they continue to change. Yet Missourians do not jump at change for change sake. As a result, the pace of change is slower here than elsewhere, and in Missouri there is little commitment to pursuing bold proactive or innovative change, or to pursue fiscal efficiency.
-

In specific, consider these few observations:

- ✓ There is a trend for change but the pace is very slow. The number of people residing at the habilitation centers has decreased since 1987. The number of people receiving Home and Community Based waiver services has gone up every year since 1989; 6,290 people received HCB services in 1997, up from 338 in 1989. And Missouri is presently expanding its family support efforts involving initiation of the “Family Directed Support Services” program resulting from recent \$4.2 million allocation. Yet when compared to progress in other states, these changes have come at a markedly slower pace. We note that:
  - ⇒ Six states and the District of Columbia have closed their state institutions (i.e., NH, RI, VT, WV, NM, ME), with several others seemingly on the verge (e.g., HI, AZ, MN, WY). Nationwide, from 1993 to 1997 the number of people served in public institutions has dropped by 23.7%, from 71,000 to a little less than 54,000 (Prouty & Lakin, 1998). Yet in Missouri, after a series of facility closures from 1988-1993, there has been little - if any -- reduction in the Habilitation Center census since then. There are no current plans in Missouri to affect the number of people living in Habilitation Centers. In 1997, 101 people were admitted to Habilitation Centers; there were 77 discharges and 22 residents passed away.
  - ⇒ Over 110,000 people with developmental disabilities nationally enjoy the benefits of regular community jobs through application of supported employment services. Here in Missouri, Braddock et al. (1998) report that in 1996, 336 people received supported employment services funded through DMRDD. We are uncertain of the state’s overall effort surrounded supported employment services, given that other state or local agencies (e.g., Division of Vocational Rehabilitation, county Senate Bill 40 Boards) may also be offering supported employment services. Yet, the evidence clearly suggests that Missouri has not kept pace with efforts in numerous other states to support people in integrated community jobs.
  - ⇒ Most people with developmental disabilities live home with family or other loved ones. This is especially true where young children are concerned. Yet, in Missouri we find that only about \$13.3 million of the \$486.5 million (2.7%) spent on developmental disabilities services is spent on family support. The recent allocation of \$4.2 million for the Family Directed Supports Program will help, but Missouri could do more to support families. Yet several states have pushed well past Missouri to act more proactively to build better coordinated and funded efforts to support families (e.g., NH, PA, MI, AK, UT)

I never give them hell. I just tell the truth and they think it's hell.

Harry Truman

- ⇒ Many states are presently exploring the concept of self-determination and its implications for system reform. In 1997, the Robert Wood Johnson Foundation awarded planning grants of \$100,000 to \$400,000 to 18 states to develop new means for addressing individual needs consistent with the principles of self-determination. The next year, ten more states received smaller grants to promote similar change. Missouri did not apply for either of these grants.
- ✓ Changes are made mostly at the margin. Most would agree that the service system can and must be improved. Yet without cohesive vision and purpose, efforts to improve services too often are undertaken in isolation and are built as a separate part of the existing system. New programs start up, but older programs remain. In some ways the Missouri system is a living museum where service programs generated over the past 25 years may be observed. Each program may have been “cutting edge” in its time, but now too many are time worn and out of sync with emerging best practices. Over time, the system has become a complicated puzzle that seems inaccessible and impenetrable to service recipients and their families. “Change” is pursued more as a means of simply trying something new, rather than as a means of revitalizing past practices while pushing forward.
  - ✓ There are strong and separate service “silos” at work. In Missouri’s system there are “silos” of service delivery that promote inefficiency and fragmentation in purpose. This observation is not a new one. The Department of Mental Health’s 1997 *Strategic Plan* plainly lists “Breaking Down Silos” as one of its top strategic issues to resolve. The issue is stated as follows:

*“The degree of DMH division separation and autonomy causes inefficiency, confusion and conflict with other government agencies, internally in DMH and in the community” (DMH 1997 Strategic Plan, p. 40.)*

Such silos are also easily observed regarding developmental disability services, especially when multiple state agencies are at work (e.g., DESE and DMRDD) and especially where department policies are inconsistent. For instance, where DMRDD may seek to expand supported work opportunities, DESE through its Sheltered Workshop Section may act to promote sheltered employment.

Separate silos may also be at work within state agencies. Within DMRDD, for example, actions may be taken to expand family support or supported employment services, even while equal action is taken to maintain habilitation centers or other congregate options.

Nothing is less productive than to make efficient what should not be done at all.

Peter Drucker

In each silo there are measures of success and people work hard to succeed. Each part succeeds on its own terms. But success in independent silos is less than what it could be overall. Further, it undercuts the application of cohesive statewide leadership for change. At issue is whether or not this fact is acceptable to Missourians.

**4. There is an inconsistent application of developmental disabilities policy across Missouri.** Individuals and families have every right to expect equal access to publicly-funded services and supports. How the service system responds to their needs should be the same regardless of whether they live in Albany, Kirksville, Sikeston. St. Louis or Jefferson City. Even-handed treatment promotes citizen trust and confidence in the system.

The eleven DMRDD Regional Centers serve as the local point of entry for the majority of services and supports that are underwritten by public funds. The Regional Centers coordinate the development of consumer personal plans and make decisions about how state dollars are spent. DMRDD establishes policies that Regional Centers are to follow in interacting with individuals and families.

But today, it is too often the case that “what you get depends on where you live.” Services and supports authorized in some regions are not made available in others. Our discussions, for example, have revealed differences in how the Choices for Families program operates region-to-region. Further, there are differences among the regions in offering individuals and families choice of service provider and the extent to which preferences are honored.

As a consequence, the system’s customers are not certain that they are being treated evenhandedly. Policies followed in one region are out-of-bounds in others. Moreover, there are differences among the regions in the extent to which regional centers regularly and actively consult with individuals, families and other stakeholders to solicit feedback concerning regional center operations and how they might be improved.

These circumstances are clearly inconsistent with our stated principles. People with developmental disabilities and their families expect that the system’s response to their needs will be equitable and evenhanded regardless of where in the state they live. This is not always the case in Missouri. At issue is whether or not this fact is acceptable to Missourians.

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Over the past 25 years, services for people with developmental disabilities in Missouri have come a long way. Many have worked hard to establish the system that serves so many in Missouri. In making our observations about the current system we do not intend to debase these past and current efforts. Rather, we seek to call attention to

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shortcomings in the present system that must be addressed. We ask again: **Are these facts acceptable to Missourians?**

Our system of services and supports for people with developmental disabilities must do better. The system works well for some, yet there are many barriers that prevent the system from serving as a reliable source of assistance so that all people with developmental disabilities can take their rightful place in our communities. We need to erase these barriers and make fundamental changes in our system. We must make changes, not simply for change sake, but because it is indicated by the evidence. **From the “Show Me” perspective, we have been shown.**

# 4. Recommendations

In 1997, at least 24,445 Missourians received developmental disability services. The human and fiscal effort expended to deliver these services is greatly appreciated.

Yet, our analysis of the current system reveals numerous serious shortcomings that must be addressed if we are to continue to improve the system and meet the challenges ahead.

Reforms must be undertaken to assure that the system operates more consistently with our stated guiding principles. These principles emphasize community inclusion, self-determination, fiscal responsibility and collaboration among all those concerned.

Underlying these intents is a simple core principle:

*Resources for supports in the State of Missouri must be allocated and expended from a person-centered perspective rather than a provider centered perspective. Individuals must be in control of their allocated resources for services and supports and how they are delivered.*

Members of the Customer Leadership Initiative generated and discussed numerous recommendations for reform related to developmental disability policy and practice. These recommendations touched upon changes regarding:

- ✓ The future of the habilitation centers;
- ✓ The continued residence of people with developmental disabilities in nursing homes;
- ✓ The numbers of people who are awaiting services -- the “waiting list;”
- ✓ The need for increased investment in family support services;
- ✓ The need for performance standards that are consistent with the guiding principles, and to spend money in ways that are consistent with these standards;
- ✓ The need for cohesive statewide leadership at the state and local levels to emphasize action that is consistent with the guiding principles;
- ✓ The need for greater consistency in services across the state;
- ✓ The need for additional resources, especially the need to increase participation in the community waiver program;
- ✓ The need for more options in the community for supported living and employment;

From this discussion, four primary recommendations stood out. Of all the actions -- large and small -- that could be taken to improve developmental disability services in Missouri, we urge that these four recommendations be embraced and put into practice.

In doing so, we recognize that the Missouri Planning Council for Developmental Disabilities (MPCDD) is the official advisory body for the state's developmental disability system. In that capacity we also recommend that the MPCDD assume the leadership role in organizing collaborative efforts to make these four recommendations a reality.

### **Primary Recommendations**

1. Resources for supports in the state of Missouri must be allocated and expended from a person-centered rather than a provider centered perspective.
2. Missouri must provide people with developmental disabilities the opportunity to select, find and maintain integrated employment.
3. Regional Councils must play an active role as conduits for grassroots input to promote consistent application of policy throughout Missouri.
4. Missouri policy makers should build system capacity for serving people with developmental disabilities in ways that are consistent with our guiding principles.



**Resources for supports in the state of Missouri must be allocated and expended from a person-centered rather than a provider centered perspective.**

This recommendation lies at heart of our vision for system reform in Missouri. It is consistent with our stated core principle and other defining principles (See Chapter 2). It is consistent with momentum that is growing nationally in support of self-determination and community inclusion. And it signals that to succeed we must be willing to learn to do things differently, not simply get better at doing the things we are already doing.

In Missouri, the prevailing means for delivering supports are facility-based. We recognize that there are features of the present system or specific programs that exemplify person-centered practices. But these are more the exception than the rule. Generally, in Missouri resources for support are given to those providing the

supports either by contract or through fee for service reimbursement. Decisions of what, how, and where supports are to be provided, at best, may be a shared activity with the person who is receiving the supports. However, more often these decisions are made with little direction from the person involved. Decisions are primarily owned or controlled by individuals empowered by virtue of professionalization or position. In essence, control of who provides the support almost always rests with the provider organization.

Person-centered support systems dramatically depart from these traditional practices. In several states policy makers are exploring means establishing new service structures that promote self-determination, community inclusion and fiscal responsibility. “Participant-Driven Supports” is one term that is used to describe these emerging systems.

Participant-driven support systems require that people/families, rather than third parties, exercise choice over how dollars are used (within certain parameters); that supports be obtained within a fixed dollar budget; and the person/family carries some amount of risk if the budget is improperly used (See Smith, 1995). This approach is consistent with emerging trends in the field because it promotes community life, strengthens self-esteem and facilitates empowerment among service recipients. It may also contribute to cost containment. Proponents argue that the approach will improve provider performance because of its emphasis on “customer first” behavior. Customers (i.e., participants) who do not find what they want, at a price they consider fair, will go elsewhere to make their purchases.

While there may be countless variations on this theme (See Agosta & Kimmich, 1996), we note five fundamental characteristics (See Appendix B):

1. Individuals have a person-centered plan for support and control over pre-authorized budgets that can be used flexibly to accommodate the needs specified by the individual (within budget limits).
2. Individuals have a choice of service suppliers. Providers and others act as authorized merchants -- where participants may “shop.”
3. A “risk pool” is established to help offset any risk that an individual accepts when working from a pre-set budget limit.
4. Funds are set aside to meet administrative and other overhead costs for managing the system, specialized services, or other administrative needs.
5. Individual have choice over the amount of control and responsibility one accepts in managing their own person-centered plan.

While considering participant-driven approaches we thought through two potential prototypes. One involved use of a “micro board” to assist individuals to gain increased control over their services and supports. A micro board consists of family or friends who agree to participate with an individual with developmental disabilities to control his or her allocated resources. The board may even incorporate to formalize its relationship with the individual. Another prototype illustrated a conceptual sketch of how a participant-driven system could work in Missouri (See Appendix B).

To translate these concepts into practice, policy makers must step forward to plan, test and implement participant-driven approaches in Missouri. They may be both modest and bold in their course.

- ⇒ **At the least, means for assisting people with developmental disabilities to establish micro boards should be explored and tested.** By doing so, Missouri can go far to promote self-determination for individuals without needing to pursue dramatic system change at the onset.
- ⇒ **Past this modest step, DMRDD should work with people with developmental disabilities, family members and others to design an approach to participant-driven supports that fits Missouri.** As the concept unfolds, any statutory or fiscal barriers should be identified and systematically removed or accommodated. A final product of this work should be a prototype that could be tested in selected regions.
- ⇒ **DMRDD should commit to implementing in selected regions a participant-driven support system within two years.** Like other states who are participating in the RWJ Self-Determination Projects, there is no reason why Missourians could not work together to develop and implement one or more pilots to explore how best to proceed.



#### **Missouri must provide people with developmental disabilities the opportunity to select, find and maintain community integrated employment.**

Fundamental to life in the community is the opportunity to work. When community service systems were first established in the early 1970s, however, emphasis was placed on services that tended to cluster people with developmental disabilities together in various daytime activities, including sheltered workshops and day habilitation centers.

Since the early 1980s, best practices have steadily pushed away from these early models. Supported employment approaches promote the idea that people with developmental disabilities, given a variety of supports, are capable of working in

regular community jobs. These supports can include direct support on the job from program staff or co-workers, worksite modifications, assistive technology, or modifications to work routines (e.g., job carving). Workers may be placed on individual jobs or a few may work together at a job site.

The idea is to shape the job to the individual as much as possible, teach the worker how to perform the job, and set in place any human or material supports the individual needs to complete the work. Ideally, paid staff seek to fade out their presence, leaving individuals to work their jobs without program support, but with natural support as is needed (e.g., co-workers, existing employer sponsored training programs).

Integrated employment practices are more consistent with contemporary values that stress community inclusion and self-determination than previous service models. More than that, having a well paying job in the community promotes financial independence, improved self worth and a greater sense of participation and contribution to one's community. Yet a few may have disabilities so severe that regular work seems out of reach. Some may prefer continued attendance in a sheltered environment. And others may prefer not to work at all. Still, national experience shows that over 110,000 people with developmental disabilities are working in regular community jobs. At issue is the **opportunity** individuals have to seek and maintain community-integrated employment.

In Missouri, we find that such opportunity is limited in some areas and lacking in others. The first sheltered workshop in Missouri was established in Sedalia about 30 years ago with the passage of Senate Bill 52 in 1965. Today there are about 90 sheltered workshop (non-profit) corporations operating throughout the state, employing more than 8,000 people. Complementing these workshops, daytime habilitation centers serve approximately another 5,000 people across the state. Because of their Medicaid funding, in the past these centers cannot perform contract work, focusing instead on habilitative instruction (e.g., work readiness training, functional academics, daily living skills). Supported employment services, first made available in Missouri in the 1980s, are not available to a great many people.

Precise numbers were not available to us, but it is clear that the state's primary fiscal investment rests with sheltered approaches. Comparatively, less is spent on integrated employment. Not only is the state's performance out of step with our stated principles, but given the performance of other states we conclude that Missouri can do much to change these circumstances.

We recognize that the current spending patterns did not unfold overnight, but rather evolved over time given a steady line of policy decisions. From our view, we

primarily observe a lack of cohesive commitment -- backed by fiscal investment -- across state agencies (e.g., DESE, DMRDD) and Senate Bill 40 Boards to supported employment. For example, we note that:

- ✓ There is a unit inside of DESE -- The Sheltered Workshop Section -- that is dedicated to the promotion and development of sheltered workshops. No other comparable unit exists for any other daytime option. In fact, the current DESE internet website posts a variety of information on sheltered workshops, including instructions on how to start one. There is no complementary information display related to supported employment.
- ✓ Missouri's policies governing eligibility for programs like Medicaid actually discourage individuals from earning a decent wage.
- ✓ Service providers indicate that it is very difficult to maintain integrated employment programs due to current billable rates.
- ✓ There are contradictory requirements regarding which agencies or individuals can deliver employment services. Sheltered workshops, for instance, are not required to be CARF certified while supported employment agencies must be. This requirement may pose a significant deterrent to small employment agencies.
- ✓ Sheltered workshops cannot legally hire workers without disabilities to perform contract work, thereby eliminating the potential for promoting "affirmative industry" practices where the shop itself becomes an integrated workplace. This regulation may also discourage shops from losing their best workers to supported employment, given a pressing need to complete contract work.
- ✓ Eligibility for sheltered workshops, determined by the Division of Vocational Rehabilitation (DVR) (under DESE), routinely pits sheltered work against supported employment. To become eligible for sheltered work an individual must be deemed "unemployable at this time," and so is ineligible for supported work. If deemed "employable" and eligible for supported employment, however, one cannot be eligible for sheltered work. These routines create an "all or nothing" predicament for workers with disabilities, ultimately discouraging individuals from trying a community job as an alternative to or in combination with sheltered employment. We understand that DVR is taking steps to alter this eligibility routine, but we are uncertain of the status of their efforts or its effects.

This circumstance also stirred our curiosity when we discovered that 69% of the total revenue for sheltered workshops in 1996 (\$54.6 million of \$79.2 million) was generated by contract work -- work performed by individuals judged to be "unemployable at this time." The revenue is largely used to pay for the costs of

operating the workshops (e.g., staff wages, facility costs). In essence, sheltered work employees with disabilities, who earn on average \$1.64 an hour -- are in great part paying for the operating expenses of the sheltered workshops.

While the emphasis in Missouri surely is centered on sheltered day-time options, many policy makers are interested in expanding supported employment opportunities. DMRDD, for example, recently altered its Medicaid Home and Community Based waiver to include supported employment as a reimbursable service. Likewise, many providers indicate a willingness to offer supported employment services. Still, to promote a sure and steadfast commitment to community employment we recommend that:

⇒ **Relevant state leaders convene an “Employment Summit” to declare their commitment and take action to assist people with developmental disabilities to find, select, and maintain employment in real community jobs.**

Participants should include principle policy makers representing DMRDD, DESE, and the Division of Employment Security. At this summit, participants should take action on the following:

- ✓ Reaching consensus on a policy direction to emphasize employment opportunity for people with developmental disabilities.
- ✓ Reach consensus over a variety of steps that the participants will take cooperatively individually or collaboratively to remove barriers to and create incentives for integrated employment. This actions could include:
  - Making statutory changes as needed to establish a more coherent and productive decisionmaking structure regarding employment policy.
  - Working with Senate Bill 40 Boards and service providers to assure that people with developmental disabilities and their families are fully informed of the state’s commitment to community employment and of the options available to them. Support statutory change to the enabling statute for sheltered workshops to permit hiring of non-disabled workers to perform contract work.
  - Conducting a top-to-bottom review of Missouri’s current policies that govern eligibility for programs like Medicaid to pinpoint the changes necessary so that people who obtain regular jobs at decent wages will benefit from employment (See accompanying Box on the next page). This review should identify changes in state law or regulations that would align Missouri’s policies to take advantage of options in federal policy that would allow people to retain as much of what they earn as possible.

## **Eligibility For Medicaid, People With Developmental Disabilities and Missouri**

Many people with developmental disabilities have very low income. They rely on the Medicaid program to pay for their health care. Also, in order to receive services through programs such as the home and community-based waiver, they must be qualified for Medicaid.

Generally, under federal law, people with disabilities qualify for Medicaid in one of two ways: they receive federal Supplemental Security Income (SSI) payments or they qualify under various “optional” categories that a state may establish. SSI recipients who work can keep some of the money they earn without losing benefits. For people who do not receive SSI, a state can establish its own rules concerning how earnings are treated for purposes of Medicaid eligibility.

As a result of decisions that were made when the federal SSI program was launched in 1972, Missouri decided to retain more restrictive eligibility policies. Technically, Missouri is what is termed a Section 209(b) state. One example of these more restrictive policies is that federal policy allows individuals to have up to \$2,000 in assets (e.g., money in a savings account). In Missouri the limit is only \$1,000. People who earn money that would take them over the \$1,000 amount are usually urged to spend their “excess” income to avoid losing Medicaid benefits. In other cases, people with “excess” income find their earnings attached to pay for the services they receive. When this happens, they in effect are being taxed at a 100% rate when they earn “too much”.

By and large, the circumstance that Missourians with developmental disabilities find themselves in is that when they earn “too much”, they will see their earnings taxed at a high rate or they will face the loss of Medicaid benefits. There are changes that can be made in Missouri’s policies that would permit people to retain more of what they earn without facing the loss of vital benefits or finding themselves turning over what they earn to the state. One such change is to rethink Missouri’s status as a Section 209(b) state so that Missouri’s policies are no more punitive than federal SSI rules. The second change is to modify the rules for eligibility for long term services so that more of what people with disabilities earn can be protected.

- Altering the routine for determining eligibility for sheltered work and supported employment to encourage individuals to move more freely between sheltered and community work.

- Correcting the contradictory requirements regarding certification of what individuals or agencies can deliver employment services. New policies must maximize the sources of employment services throughout the state.
  - Distributing information to people with developmental disabilities, families and providers regarding supported employment, including development of a informational website to complement the current DESE site on sheltered employment.
- ⇒ **State level policy makers work with people with developmental disabilities, families, Senate Bill 40 County Boards, service providers, and others to develop a "Missouri Voucher to Work" service option.** Such a plan would establish a "employment voucher" where individuals can purchase their employment services from the provider of their choice, at an individually agreed price, and for the outcomes they seek. This plan is consistent with our core principle requiring that resources for support be allocated and expended from a person-centered perspective. In addition, it follows precedent in Missouri (i.e., the Personal Assistant Care Program administered by vocational rehabilitation) and nationally (e.g., employment voucher demonstration projects).
- ⇒ **DMRDD strongly pursue its intent to fund increasing amounts of supported employment services through its Medicaid Home and Community Based waiver.** In doing so, it should offer providers the training and technical assistance they may require to offer the service.



**Regional Advisory Councils must play an active role as conduits for grassroots input to promote consistent application of policy throughout Missouri.**

Many years ago, Missouri set up its *Regional Advisory Council* network in parallel with the Regional Centers so that individuals, families and other stakeholders could come together to assess services from a local, grassroots perspective and advise Regional Centers. In some regions, there is an active and productive partnership between the Regional Center and the Regional Council. In others, however, there is a greater distance between the Regional Council and the Regional Center. Over the years, however, the Regional Advisory Councils' role has been eroded.

Asking for and listening to individuals and their families concerning how well the system is performing is important in achieving better results. The role of Regional Advisory Councils as conduits for innovation needs to be rekindled. Some of the best ideas and innovations that have improved Missouri's system have come from Councils.

To ensure that individuals and families are receiving even-handed treatment regardless of where in Missouri they happen to live, we strongly recommend that the original role and purpose of the Regional Advisory Councils be reaffirmed. Regional Advisory Councils oversee consistent implementation of DMRDD policies around the state. DMRDD should value and affirm that Regional Advisory Councils can play an important role in promoting accountability and consistency in the application of state policies by Regional Centers. Asking and listening to customer views concerning how well the system is operating is important in achieving better results and improving trust.

The process of strengthening the role of Regional Advisory Councils should start with achieving the buy-in of all Regional Advisory Councils with the values and principles that have been articulated by the Missouri Customer Leadership Initiative. The Regional Advisory Councils should embrace the fundamental premise that publicly-funded services and supports must be framed by person-centered principles and that the system must be held accountable for respecting and acting upon the needs and preferences of each individual and family. Regional Advisory Councils should initiate dialogue with their Regional Center concerning how such principles will shape the provision of services and supports at the regional level.

We recommend that:

- ⇒ **DMRDD support the advisory role of the Regional Advisory Councils.** This means that DMRDD should assist and encourage Regional Advisory Councils to: (a) monitor the implementation of state policies at the regional level, and (b) initiate discussion and action for needed policy changes.
- ⇒ **DMRDD solicit and act upon Regional Council findings and recommendations concerning state policy implementation and change.** Regional Center directors must be held accountable for following state policies. When problems cannot be resolved locally, DMRDD should provide Regional Advisory Councils with a clear avenue for referring the problem to the Division and securing its quick resolution.
- ⇒ **A role for stakeholders and Regional Advisory Councils in anticipating, recommending, and supporting changes and improvements to services is implemented.** Missouri needs to tap the knowledge and energy of all its citizens to improve the system's ability to deliver the supports that people and families want.
- ⇒ **A mechanism is developed to promote collaboration and effective communication among the Regional Advisory Councils, the DMRDD and the Missouri Planning Council for Developmental Disabilities.** Clearly, if Regional Advisory Councils are to be more active in monitoring how consistently state policies are being implemented, then a mechanism will need to be put into

place that promotes effective communication among the Councils. The Missouri Planning Council can and should facilitate this communication. Working with the Regional Advisory Councils, the state planning council can aid in identifying possible topics that would be a focus of Regional Council monitoring activities and collaboration.

- ⇒ **Regional Council members receive the support they need in the form of training and learning opportunities to play their role effectively.** Certainly, if the Regional Advisory Councils are to be more active in monitoring the application of state policies at the regional level they will need to be well-versed in those policies. Both DMRDD and each Regional Center should routinely make available opportunities for Regional Council members to be briefed on policies and procedures as well as observe Regional Center operations.
- ⇒ **The State of Missouri should invest in grassroots advocacy by furnishing financial and in-kind support to the Regional Advisory Councils.** The Regional Advisory Councils depend on Regional Centers for in-kind support. The extent to which such support is available to the Regional Advisory Councils varies from region-to-region. For Regional Centers to obtain grassroots input and leverage new community resources, the DMRDD must invest in Regional Advisory Councils.



### **Missouri policy makers should build system capacity for serving people with developmental disabilities consistent with our guiding principles.**

The Missouri state population stands at about 5,414,000 people. A prevalence rate for developmental disabilities of 1.8% suggests that approximately 97,452 people in Missouri have a developmental disability. Yet in 1997, DMRDD served only about one quarter of this number, with many receiving case management services only. A recent DMRDD study of current consumers (DMRDD, 1998) shows that 314 people over age 65 and another 1,378 between 40-65 receive case management only. As these individuals and their caregivers grow older, one can easily speculate that many of these individuals will soon need more substantial support.

In addition, DMRDD also reports a continued stream of people that it finds eligible for services each year, placing increased pressure on the system to expand its capacity:

- ✓ More than 600 children (under age 6) have been determined eligible in each of the past six years;
- ✓ Typical growth for DMRDD is 1,200 consumers per year;

- ✓ Between 400-500 students exit the school system each year, seeking major supports; and
- ✓ Few people who receive services from DMRDD exit the system.

And these are just the individuals that are known to DMRDD. One is left to imagine under what circumstances so many other Missourians with developmental disabilities have not come forward to request services. Some may have no present need for services, their needs are being met by independent means or by family or friends. Some may simply not request public assistance. Others may have needs that they feel the system cannot or will not meet. Within these categories individual factors may well change (e.g., an aging caregiver who can no longer provide support), resulting in that person coming forward to request services. But others may need and want services but have not yet been identified.

Missouri's present system falls short of meeting the legitimate needs of people with developmental disabilities today. The price of this shortfall is that people who need such supports to meet day-to-day challenges to become productive, contributing members of their communities are being short-changed. Demand for services and supports is greater than the public system is able to meet today. This demand will not disappear. Missouri needs to expand capacity today and adopt policies for the future that will ensure that people who have legitimate service needs will have those needs met. Parent caregivers need the assurance that supports will be there when they no longer are able to continue to provide care.

Underlying the three previous recommendations is an expectation for service approaches that are person-centered -- but also fiscally responsible. These recommendations have the potential for promoting self-determination, community inclusion, and a unified vision of the future.

We expect that such action will increase fiscal efficiencies and help to eliminate chronic system difficulties that make the system appear complicated, inaccessible and ultimately impenetrable to people with developmental disabilities and their families. Additionally, we expect that by using the money already available with greater direction and purpose, resulting increases in efficiency will expand the capacity of the system to serve more people. Indeed, the cost for not taking these steps should be unbearable to all Missourians. To help correct these circumstances, we recommend that:

- ⇒ **DMRDD design and implement a coordinated and reliable means for determining the current and future demand for developmental disability services.** Each day children with developmental disabilities are born. These are individuals who may well need developmental disability services during their lives. In addition, we recognize that America is graying, a trend that certainly

includes people with developmental disabilities. And where these individuals live home with their families, we recognize that their family caregivers -- often their parents -- are aging as well. These population demographics are observable and to some extent can be used to predict the future demand on developmental disability systems.

At present, waiting list data in Missouri is collected by multiple sources (e.g., Senate Bill 40 Boards, Regional Centers), but these data are not systematically tied together to assure their accuracy and reliability. Moreover, they do not always present a clear picture of the type of support a person or family needs.

To have a better understanding of what must be done to meet current and emerging service demand, DMRDD must develop a reliable tracking system to:

- ✓ Take accurate stock of relevant population demographics related to the incidence and prevalence of developmental disabilities, as well as to gage the age of parent caregivers.
  - ✓ Create an environment statewide where people can easily come forward to make their needs known.
  - ✓ Assure that the needs indicated by individuals pertain to the “urgency of need” and the type of support that is needed. Individuals should not be encouraged to specify service types (e.g., sheltered workshop, supported living). Such practice amounts to a channeling of demand into preset categories, undercutting opportunity to explore preferences for emerging or innovative approaches to service delivery. Rather, individuals should be asked to specify the types of general support they need (e.g., help to get and keep a day time job, a place to live and needed residential support).
  - ✓ Create a coordinated means of tracking needs across multiple data collection points. DMRDD offices should not be the only place where individuals can make their needs known. Other partners can be utilized, included county Senate Bill 40 Boards, parent networks and People First chapters. The idea is to create a statewide and decentralized means of tracking needs, but to do so systematically to assure data accuracy and reliability.
- ⇒ **Missouri state and local level policy makers maximize use of Medicaid funding to expand system capacity consistent with previously stated guided principles.** Missouri's present Medicaid matching rate is 60.7% (i.e., for every 39.3 cents that Missouri provides, the Medicaid program will supply another 60.7 cents). We recognize that much has already been done to

increase the use of federal reimbursement through Medicaid to fund Missouri developmental disability services.

Policy makers must continue to examine ways to leverage additional federal reimbursement to promote a person-centered service system. For instance, with supported employment now a waiver service option, dollars presently earmarked for day habilitation maybe matched for federal reimbursement to deliver supported employment services. Likewise, certain family support funds may also be creatively matched within the waiver. In this regard, new money recently allocated for “Family Directed Support Services” may in part be used within the waiver program.

- ⇒ **Missouri policy makers and advocates establish annual targets for service expansion and then actively seek appropriate state and federal revenue.** Based on findings resulting from the waiting list initiative noted above, policy makers will be able to request with confidence increases in agency budgets to accommodate the documented demand. More than that, by engaging people statewide in collecting the data, needed political support for increased appropriations will be stimulated.
- ⇒ **Missouri policy makers and advocates assure that any new money that comes into the developmental disabilities system is distributed consistent with person-centered principles.** As noted in Chapter 3, Missouri has developed a tradition of establishing a variety of programs, but without commitment to any unified vision. The result is that Missouri offers a living museum of all types of services, some contemporary and others clearly timeworn.

Breaking from this tradition, policy makers should commit to developing a person-centered system by investing any new money into approaches that are consistent with person-centered principles. The concepts and action steps previously presented in Recommendations 2 and 3, on participant-driven supports and employment, provide a clear direction for future spending.

- ⇒ **Missouri policy makers should forge partnerships with the advisory network in Missouri, including people with developmental disabilities and family members to shape policy and practice.** A commitment to person-centered principles and related dollar investments are good first steps. Successful system reform, however, will depend on establishing a strong partnership with the very people who are receiving services.

Believe in  
Empowerment  
  
Invest In  
Empowerment

To assure their effective participation in a person-centered system, policy makers will need to invest directly in service recipients. They may do so by assuring that:

- ✓ At a systems or strategic level, people with disabilities (as well as family members and guardians) have opportunity to shape policy and practice. To assure such partnership, resources must be set aside to offset the costs of participation and/or for needed training or technical support.<sup>2</sup>. Recommendation 3 on Regional Advisory Councils is certainly consistent with this action step.
- ✓ Make available to service recipients and family members information on how a person-centered system could work. Such information, delivered systematically through periodic newsletters, local focus groups, conferences and other means, will steadily develop an informed participant constituency, one that will be better prepared to press for and test innovative approaches to service delivery.

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<sup>2</sup> HSRI is compiling a nine chapter “curriculum” designed for self advocates entitled *My Voice, My Choice*. Missouri is a participating field test state. The topics covered will provide self advocates with the information related to developmental disability systems, self-determination and fiscal responsibility.

# 5. Concluding Remarks \_

This report summarizes a year's work by the Missouri Customer Leadership Initiative. During this time we explored numerous issues and learned a great deal about developmental disabilities services in Missouri. We did not always reach the same conclusions or agree about what needs to be done. Change always imposes choice, and choice often stimulates candid discussion and disagreement. For us, it also brought deliberation and finally consensus over what must be done in Missouri to improve services for people with developmental disabilities. We stand strongly committed to a core principle dedicated to a person-centered way of doing business. We believe that resources for supports in the State of Missouri must be expended so that individuals are in control of their allocated resources for services and supports and how they are delivered. This document reflects our strong commitment to translate this vision into practice across our state.

The four primary recommendations we offer (See Chapter 4) are consistent with this theme and we expect that they will serve as a basis for widespread systems change in Missouri. We are well aware that in pursuing this vision numerous procedural and technical issues must be resolved. Toward this end, we encourage the state's professional community to embrace the work we have done and apply their expertise to addressing these issues.

In addition, we recognize that there are political obstacles to overcome, given that there is a long history associated with the present way of delivering developmental disabilities services in Missouri and that hard change is seldom embraced with enthusiasm anywhere. Further, we recognize that the proposed system may not be for everybody. Some individuals may prefer to receive services as they do now.

"In the 1960's and earlier we were treated like plants. You fed us, clothed us, kept us warm, and wheeled us out to feel the sun.

In the 1970s and 80s you discovered we could be taught -- we could learn -- and we were treated like pets. You taught us all types of tricks and we stood by your side.

But now it is the 1990s. We are not plants. We are not your pets. We are people like you and we want to be treated as real people.

We want the same opportunities as anybody."



Dirk Wasano, Chair  
Consumer Empowerment Committee  
Hawaii Planning Council on  
Developmental Disabilities, 1994

Creating service options where people with developmental disabilities -- who are customers rather than service recipients -- control their lives is the cornerstone concept of a person-centered system. We are aware of the difficult steps that lie ahead to translate this vision into reality, and the need for collaborative action to guide a transition to the new system. Our recommendations can only be implemented if all parties concerned with the well-being of people with developmental disabilities in Missouri work together, including "customers," Senate Bill 40 Boards, Regional Advisory Councils, service providers, the MPCDD and state agency policy makers.

In the end, no single constituency or group of people should be asked to bear the responsibility for change alone. We must all be willing to take on our own share of responsibility; We must be willing to leave the past for the future.

Such proactive action is not new to the developmental disabilities field. The service system has changed enormously over the past 25-30 years. Fundamental to the changes over these times has been a willingness to change and the acceptance of a degree of uncertainty associated with change and reform. People left institutions for life in the community. People left their group homes for apartment living. Others left their sheltered day program for an integrated community job. While such change was for the most part welcomed, these shifts were not unanimously cheered and came with some potential jeopardy mixed in. These changes required innovation and cooperation among many. We succeeded then. Together, we can succeed again.

For the moment, the most pressing issue centers on the amount of responsibility we all will be willing to take.

- ✓ **If you are a state policy maker or Senate Bill 40 Board member, what responsibility will you take** to develop the new administrative structures needed to place people with disabilities in control of the supports they receive?
- ✓ **If you are a service provider, what responsibility will you take** to be prepared to participate in a more competitive market, one that will reward agility and those who respond best to the support preferences of people with disabilities?
- ✓ **If you are involved with a local or state level developmental disability advisory agency or board, what responsibility will you take** to provide sound advice and leadership in helping to reform the service system?
- ✓ **If you are an advocate or concerned citizen, what responsibility will you take** to do what you can to assist individuals with developmental disabilities to participate in the planned changes or simply to assure that others do their job?

"You might be on the right track,  
but you'll get run over if you just sit  
there."

Will Rogers



- ✓ **If you are a parent or family member of a person with developmental disabilities, what responsibility will you take** to assure that your loved one receives the best supports possible but also receives the chance he or she deserves to live a self determined life?
- ✓ **If you are a self advocate -- a person with a developmental disability -- what responsibility will you take** to express your life needs and dreams, make responsible choices and live your life. Further, **what responsibility are you willing to take to help lead the way in the changes that lie ahead?**

The idea that the developmental disabilities system must be significantly changed to embrace a person-centered perspective is still gaining momentum, and the direction the field ultimately will take is by no means clear. We hope that all in Missouri will agree to shoulder their share of responsibility to improve services for people with developmental disabilities. We expect that this report will be used as a guide to the state and local discussions that must unfold over the next few years. Such discussions, however, must lead to action -- action of the sort that will ultimately ensure the well-being of people with developmental disabilities, and a life in the community shaped by their own preferences. We will expect and accept nothing less.

# 5. References

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## **Appendix A**

**Services and Supports For Missouri's  
Citizens With Developmental  
Disabilities:**

**Where The Dollars  
Come From And Go To**

## **Appendix B**

### **Elements Of A Participant-Driven System**

## Appendix B: Elements Of A Participant-Driven System

Reduced to its essence, in participant-driven support systems the participant and/or family decide how limited service funds are spent. This approach is consistent with emerging trends in the field because it promotes community life, strengthens self-esteem and facilitates empowerment among service recipients.

It may also contribute to cost containment. Proponents argue that the approach will improve provider performance because of its emphasis on “customer first” behavior. Customers (i.e., participants) who do not find what they want, at a price they consider fair, will go elsewhere to make their purchases. In this context, participant-driven models do support the goal of cost containment. Smith & Ashbaugh (1995) argue that:

*Service recipients, working on limited budgets, will spend more prudently to get the most value for their money, and participant-driven arrangements will spawn a market economy in which those providers representing the most value will survive.*

This argument, which forms the basis of participant-driven approaches, promises cost containment within a context of “quality” that promotes self-determined lifestyles. For this to work, two shifts in practice are required: (a) decisions about what is “important” or “needed” should be left to the individual; and (b) only what is received will be paid for. Such an approach will increase efficiency and so reduce overall costs.

The underlying philosophy and evolving practices of the developmental disabilities field argue for participant-driven approaches. But how would the approach be structured and how would it work? Individuals with developmental disabilities and their families will need to be actively engaged to assure that the emerging service systems are:

### About That Word “Participant”

**Participant:** One who participates or takes part in something.

**To Participate:** To take part; join or share with others. (American Heritage Dictionary)

Over the years much attention has been directed toward the proper label to apply to those who utilize developmental disabilities services. Are these people “clients”, “consumers”, or “customers”? For a number of reasons, these words are not used in this primer to reflect the role that people with disabilities will play in future service systems. Instead, the word “participant” is used because it embraces an active role that pushes beyond a reflection of client-professional relationships or simple economic symbolism (consumers or customers).

In a participant-driven system, people with disabilities will help shape the structure of the system. And at a personal level, individuals will - alone or in association with others - make decisions about the lives they want to lead. In essence, they will be *active participants* in directing systems and their own lives.

- 🕒 At the systems level, designed to maximally reflect the stated needs and preferences of service recipients regarding policy and practice; and
- 🕒 At the individual level, characterized by enough flexibility that service recipients and family members (with support as needed) can direct the provision of services and supports.

At a systems or strategic level, people with disabilities (as well as family members and guardians) must have opportunity to shape policy and practice. To assure such partnership, resources must be set aside to offset the costs of participation and/or for needed training or technical support.

At a personal or individual level, participant-driven approaches require that people/families, rather than third parties, exercise choice over how dollars are used (within certain parameters); that supports be obtained within a fixed dollar budget; and the person/family carries some amount of risk if the budget is improperly used (See Smith, 1995). While there may be countless variations on this theme, the approach has four fundamental characteristics:

1. **Individuals have a person-centered plan for support and control over pre-authorized budgets that can be used flexibly** to accommodate the needs specified by the individual (within budget limits). Individuals may act alone or in association with their family members or other concerned people. Along with a budget to work with, individuals must also have access to a qualified “broker” to identify what supports are being purchased and their cost (See item 5 below for a fuller description of the broker’s potential responsibilities). The resulting plan will assure that the allocated dollars are accounted for, and that the risk for overspending the budget is minimized.
2. **Individuals have a choice of service suppliers.** Providers and others act as authorized merchants -- where participants may “shop.” Having control of pre-authorized budgets and in consultation with a personal advocate/broker, participants will be free to decide what service provider they want to deliver needed supports. In fact, the participant may decide not to choose traditional services, opting instead for alternative or informal support arrangements.
3. **A “risk pool” is established to help offset any risk that an individual accepts when working from a pre-set budget limit.** Risk is defined as the danger or probability of suffering harm or loss. Where a person accepts a pre-authorized budget to address his or needs, he is also accepting some amount of risk. No matter how well conceived the associated plan may be, there is the possibility that unforeseen events (e.g., a medical emergency, changes in the availability of staff) will place the person in jeopardy of overspending his budget. A risk pool is designed to offset such risk. The state (or an equivalent managing

entity) sets aside some amount of money to accommodate unexpected costs for all participants.

**4. Funds to meet administrative and other overhead costs for managing the system.** Administrative costs include expenses incurred by the managing entity related to overall operations of the service system. This could include costs for addressing: (a) collective concerns (e.g., determining eligibility, staff development, information management, reducing the waiting list), (b) offering specialized services, or (c) other administrative needs. Any amounts earmarked for these costs must be closely justified and subject to overall limits.

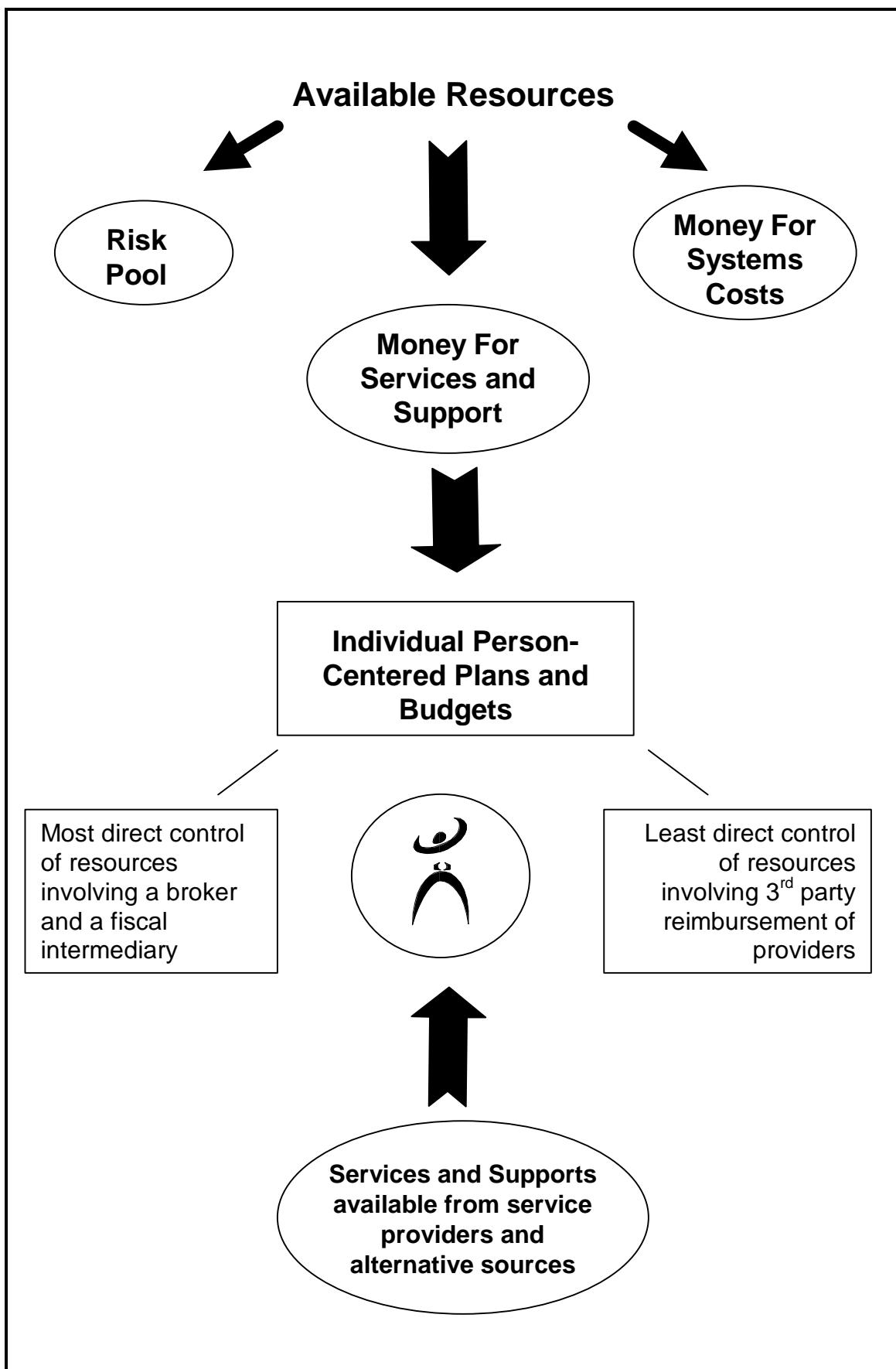
**5. Individual choice in amount of control and responsibility one accepts.**

We recognize that “one size will not fit all” and that individuals will vary in the amount of control they want to exercise. Some may want control over the types of services and supports they receive, but want no part of managing any of the fiscal transactions. For these people the system will function much as it does today, involving direct payments from payer to providers. Others, however, may want greater control over the finances; some may even prefer to pay their service providers directly. Under these circumstances, we anticipate that the individual will require the services of a “broker” or “personal advocate” and a “fiscal intermediary.”

- ✓ Brokers or personal advocates help individuals develop support plans and secure supports. The broker may well be the most important element in a participant-driven approach. This person has responsibility for assuring that the support plans: (a) honor the individual’s support preferences, (b) are within budget, (c) are sufficient to meet the person’s needs, and where a group is involved (d) are cognizant of the need to assure that sufficient funds are available to meet the needs of other members of the group. In many ways, the broker is *the* essential pivot point to the entire approach.
- ✓ A fiscal intermediary or “business agent” assists individuals to manage their budgets, satisfy any associated payroll obligations, and protect individuals from various liability claims.

The accompanying graphic (next page) illustrates how a participant-driven system could work.

- ⇒ The top portion of the graphic shows available resources that are divided into three categories: (a) money to operate the system (item 4 above), (b) money set aside in a risk pool (item 3 above), and (c) all other money to pay for services and supports.
- ⇒ Next, individuals -- participants -- must develop person-centered plans given the confines of a personal budget (item 1 above).



Finally, individuals can choose from whom they receive supports (item 2 above).

- ⇒ Throughout the decision making process, individuals can choose the amount of responsibility they want to take in managing their own affairs (item 5 above). Participants could choose to have maximum control, opting to manage their own personal budget. In this instance, participants would most likely require the assistance of a “broker” to help them make decisions and a “fiscal intermediary” to handle finances. Or, they may seek the least amount of control. Here, they may set a person-centered plan, but have limited control over exactly how their allocated resources are spent, relying instead on traditional third party payment and contracting mechanisms.

### **Potential Prototypes Developed By the Customer Leadership Initiative**

We understand that the description of a participant-driven support system given above is not at all complete and much additional work will be required to translate this concept into practice. In addition, our review of activities in several other states illustrates that there is no single way to proceed. For example, the Robert Wood Johnson Foundation recently made grants to 18 states to push ahead with their own “self-determination projects”. These projects promote new configurations of support, in combination with existing services, to empower individuals with developmental disabilities to gain control over their selection of needed services or supports. More recently, a smaller group of states was selected by the Foundation to receive a technical assistance grant to help resolve issues related to “customer driven” systems.<sup>3</sup> Unfortunately, Missouri is not participating in these RWJ initiatives.

While considering participant-driven approaches, however, we thought through two potential prototypes. One involved use of a “micro board” to assist individuals to gain increased control over their services and supports. Another illustrated a conceptual sketch of how a participant-driven system could work in Missouri.

- ✓ **Micro Boards.** In brief, a micro board consists of family or friends who agree to participate with an individual with developmental disabilities to control his or her allocated resources. The board may even incorporate to formalize its relationship with the individual. The individual (and his board) is granted a person-centered budget or service allotment (e.g., voucher) to work with. Subsequently, the individual and board (and perhaps a case manager) work out a plan for using these resources to acquire needed services and supports. This approach places the individual and his micro board in control of his own support resources, allowing flexibility and choice in their use. While considering the

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<sup>3</sup> For more information about these planning grants, contact Donald Shumway at the Robert Wood Johnson Foundation Office on Self-determination for People with Developmental Disabilities; 10 Ferry Street (#14); Concord NH 03301 -- phone: 603-228-0602

approach, we realized that there are no particular barriers in the existing system that would prevent timely implementation of this approach in Missouri.

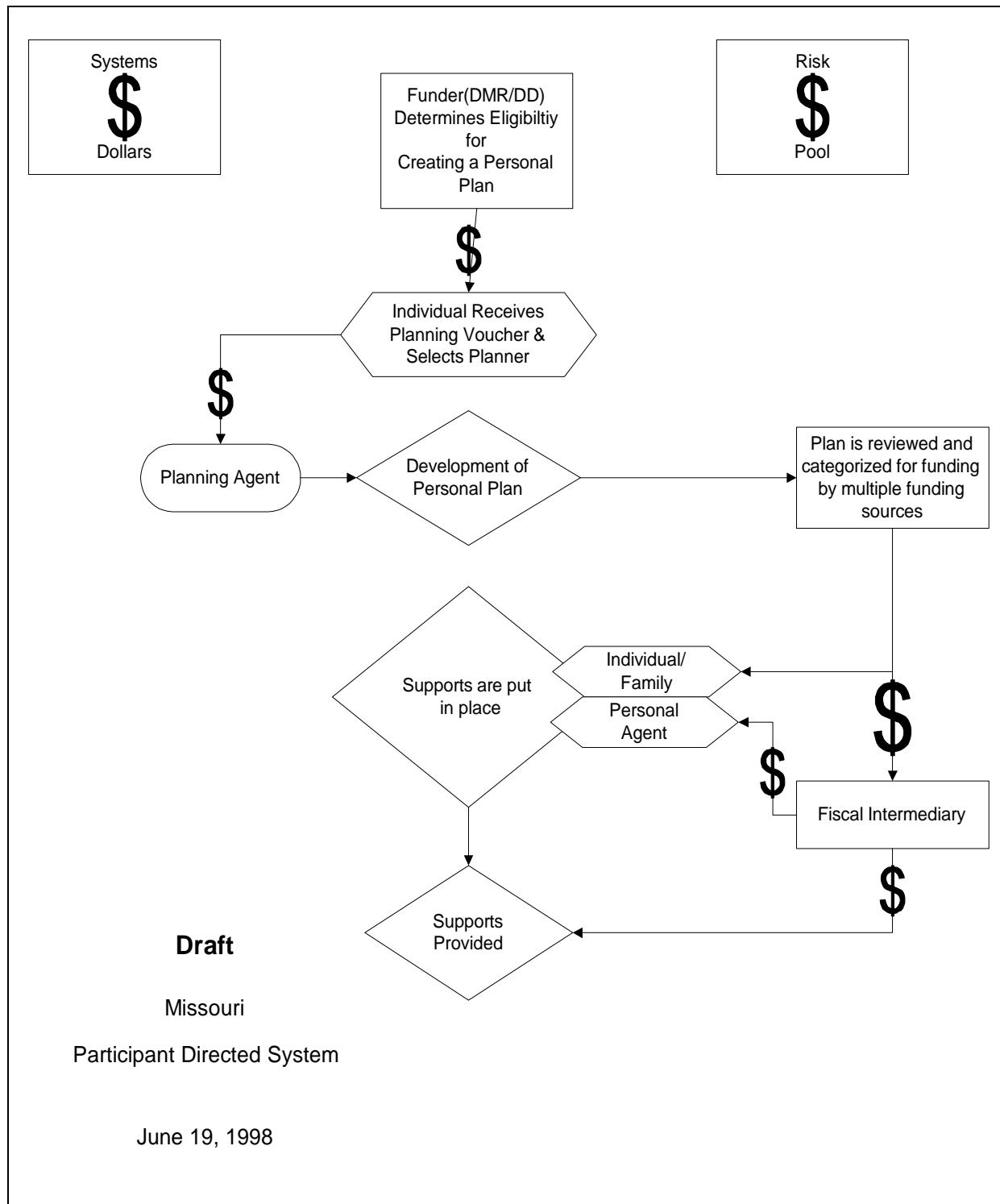
- ✓ **Conceptual sketch for a participant directed system.** The accompanying figure illustrates a potential flow of money and decisionmaking in a participant-driven system. The sketch represents just one iteration of a participant-driven system that was conceived by members of the Missouri Customer Leadership Initiative. It is by no means in “final” form, and we understand that much additional work would need to be done to work out all of the mechanics. Yet, the sketch offers a potentially useful model for implementing participant-driven supports in Missouri.

The sketch incorporates all of the five elements described earlier.

- ⇒ As shown, we anticipate resources being used for: (a) a risk pool, (b) systems management, and (c) services and support.
- ⇒ Form the “services and supports” allotment, individuals would receive a “Planning Voucher” and select a “Planning Agent.” The agent could work for the State or a private concern. The State may even require that the Planning Agent be trained and “certified” to act in this role. The agent may also continue his or her relationship with the individual, serving as a “broker”. The idea here is simply to highlight the need at the start for someone to help the individual to craft a well thought out supports plan to address identified needs. The Planing Agent would help the individual to develop a “Personal Plan” that would specify how a personal budget would be spent.
- ⇒ After the plan is reviewed and funded by appropriate authorities, the individual may secure the specified services on his own, incurring all responsibilities for managing and accounting for the budget.

Or, the individual can get some help. To account for any financial transactions he may use a “Fiscal Intermediary.” And to help secure needed services, the individual may elect to utilize a “Personal Agent” or Broker.

- ⇒ After supports are provided, the whole cycle may begin again. In fact, we anticipate that the cycle will necessarily be repeated at least annually.



## **Other Resources on Participant-driven Supports:**

To learn more about participant-driven supports and about what varying approaches are being tested around the country, please refer to any of the following resources:

- Agosta, J. & Kimmich, M. (1997). *Managing our own supports: A primer on participant driven managed supports*. Alexandria, VA: National association of State Directors of Developmental Disability Services.
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